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ABSTRACT

A major problem of long term care for the elderly is providing alternatives to institutionalization. An estimated 75 percent of all long term care provided to the elderly is from informal caregivers, usually family members who face numerous problems they are not trained to handle. A model program which provided 25 informal volunteer caregivers with training in caregiving skills was evaluated in terms of two hypotheses: (1) that commitment to caregiving and the caregiving group, knowledge of community services, confidence in caregiving ability, and a positive perception of community services would be bolstered by frequent attendance at the training sessions; (2) that as these factors increased, willingness to serve as informal caregivers would also increase. Pre- and post-test questionnaire data were obtained from 14 program participants. The results showed a negative correlation between attendance at training sessions and confidence in the performance of caregiver tasks, commitment to caregiving, and commitment to the caregiver group. Although some participants became more familiar with community services, regarded services more positively, gained in caregiver confidence, and became more committed to caregiving and the caregiver group, these changes were not correlated with attendance at the training sessions. (DPO)

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INCREASING THE EFFECTIVENESS OF THE INFORMAL SUPPORT SYSTEM IN RURAL AREAS

Research Brief

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by

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Introduction

A major problem related to long term care is how to provide alternative systems of care other than in institutions. In recent years the trend has been to deemphasize institutional care and to emphasize providing a whole continumuim of care to people in their own homes. As a result many both private and public home service agencies are bing created. Many elderly residents cannot afford the services of the private agencies, however, and it is often impossible for the public agencies to adequately reach the elderly in small communities. It has been discovered, consequently, that at least 75% of the care being provided to the elderly long term care recipients in the United States is being provided by "informal caregivers" (Pritzlaff Commission Report, 1984; Cantor, 1983; Goldstein, et. al., 1981; Branch & Jette, 1983). Most of these caregivers are spouses, children, other relatives or friends and neighbors of the care recipients (Cantor, 1983). Also, it has been pointed out that "dependency fosters a rise in assistance by family members" -- the greater the need the more assistance they offer" (Weeks & Cuella, 1981).

The problems that informal caregivers encounter are numerous. Research indicates that the majority of informal caregivers are spouses or adult female children of the ones receiving the care, who have had no training in this kind of very demanding work (Goldstein & Wellin, 1981; Cantor, 1983; Soldo & Myllyluams, 1983). There are some serious questions about the overall effectiveness of caregiving by those within a person's social network (Cohen & Adler, 1984). They tend to lack knowledge of outside help and worry about how to obtain it when and if it might be needed (Cantor, 1983; Ward, et. al., 1984; Zimmer & Mellar, 1981). It is reported that spouses are the most committed caregivers and tend to provide the most consistent care of all of the caregiver types (Soldo & Myllyluams, 1983; Goldstein, et. al., 1983; Johnson, 1983; Sherwood, et. al., 1984). They are typically motivated by a strong affective bond to the mate needing care and often they structure their entire existence around their caregiver role (Goldstein, et. al., 1981). Ironically, however, Cantor points out that they also tend to be the highest risk group of all the caregivers, in terms of developing debilitating health problems of their own and having to give up and have their spouses institutionalized (Cantor, 1983). According to Soldo and Myllyluams, caregiver efforts on the part of family members are often "last ditch" efforts to prevent their family members from having to be institutionalized (Soldo & Myllyluams, 1983). Thus, the caregiving that is being provided has not been something for which preparations have been made. Instead they take on desperation and crisis orientation.

A sense of isolation and burden have been found to be extremely important problems with caregivers (Zarit, et. al., 1982). Caregivers have identified their greatest problems as having no time

for outside interests, loss of identity, and having to live another persons life (Zimmer & Mellar).

While researchers have provided quite a thorough analysis of the problems of informal caregiving, only a few attempts have been made to improve the quality of that type of providing care. Zarit has suggested that "network therapy" ought to be utilized to strengthen the client's total network and incorporate it into the caregiving tasks to lessen the sense of burden individual caregivers often feel (Zarit, et. al., 1980). Heller, Walsh and Wilson reported on a relatively successful program to train seniors in needed skills to care for other seniors (Hellar, et. al., 1981). A program to train family members to care for the elderly in their households using operant theory methods was reported by Pinkston and Linsk (Pinkston & Linsk, 1984). Little is apparently being done, though, to create interdependent caregiver groups, to develop the confidence of informal caregivers, or to provide linkages between the formal and informal systems. The need for this kind of training is readily recognized, however, (Grobe, et. al., 1984)

Informal Caregiver Model Project

An experimental informal caregiving model project has been organized in the small rural community of Black Canyion City, Yavapai County, Arizona, where a heavy concentration of retired elderly people live. The project was a joint effort of Yavapi Catholic Social Services, the Arizona Long Term Care Gerontology Center and the Northern Arizona University Gerontology Committee.

Typical of many rural communities in Arizona, Black Canyon City is lacking in available services needed by many elderly people. It is located sixty-five miles from Prescott, the Yavapai County seat, and nearly fifty miles from the nearest metropolitian center (Phoenix) where major services are available but in another county. The community itself lacks social and health care services. Many of the elderly who live there have migrated to the community from elsewhere and lack well-established natural support systems of family and friends. Many of them either receive care from informal caregivers or provide it for someone else.

The goals of the project were to: 1) provide training in caregiving skills; 2) create an informal caregiver group identity and interdependency; 3) provide periodic respite from and support in the constant burden of informal caregiving; 4) create a cooperative linkage between the informal and the formal caregiving systems; and 5) develop a volunteer assessment and case management system linked to Catholic Social Services of Yavapai County.

Yavapai Catholic Social Services, as an agency with county-wide responsibilities to the aged, took the initiative to organize a local planning and coordinating committee. Eleven different training sessions were scheduled over a three month period. The training was divided into four sections: 1) perspectives on aging, 2) home care skills, 3) taking care of self, and 4) supportive services in Yavapai County. A total of 25 volunteer practicing and

potential caregivers were recruited from the community to become part of the caregiver group and receive the training.

A team of researchers from Northern Arizona University was recruited to evaluate the effectiveness of the program. The following hypotheses provided the basis for the evaluation: 1) the more participants became exposed to the training program and interactions of the group the more knowledge they would gain about available community servicer, the more confident they would become as caregivers, the more committed they would become to caregiving and to the caregiver group, and the more adequate they would perceive the formal services available to them in the community; and 2) the greater their knowledge of community services, confidence as caregivers, and commitment, the more willing they would be to serve as informal caregivers to a broad spectrum of elderly clients in the community.

Data were collected on the above variables via pretest and posttest questionnares. Pretests and posttests were administered immediately before and after the training sessions. Only fourteen of the original twenty-five participants completed both the pretest and posttest. Those fourteen provided the basis of the following analysis.

The major variables were measured as follows. Attendance at training sessions was used as the measure of exposure to the program and the extent of group interaction. A series of questions on participants' familiarity with available service agencies provided the knowledge of services measure. The confidence respondents expressed in doing a list of typical caregiver tasks provided the basis for an index of confidence. Commitment to caregiving was measured by a single question with five possible responses. A series of three questions on each subject's sense of belonging and identification with the caregiver group were combined to form a group commitment index. The measure of adequacy of community services was based on a single question on that subject. Subjects were asked how willing they were to perform a number of typical caregiver tasks to indicate their measure of overall willingness.

Data in this study were analyzed primarily on the gamma (for ordinal scale variables) and lambda (for nominal scale variables) non-parametric measures of association. Significance measures were ignored partly because of the extremely small number of cases and partly because no attempt had been made to do representative sampling. Our purpose was not so much to verify theory as it was to show tendencies and to develop theory.

Findings

Exposure to the training being provided and to group interaction (attendance) was a key variable in this evaluation. Attendance records ranged between seven and eleven sessions. Half had low (7 to 9 sessions) and half had high (10 to 11 sessions) attendance. An analysis of the attendance data showed that none of the hypotheses related to attendance were supported. Maximum

attendance was not associated at all with increased familiarity with available community services or increased willingness to perform typical caregiver tasks (gamma=.ooo) and negatively with perceived adequacy of those services (gamma= -.304). It was also negatively associated with increased confidence in doing caregiver tasks (gamma= -.636). It was very weakly but negatively related to both commitment to caregiving (gamma= -.280) and to the caregiver group (gamma= -.143).

It was not that no individuals gained in familiarity with services, perceived community services as more adequate, gained caregive confidence, or became more committed to caregiving and the caregiver group. In fact, 78.6% of them became more familiar with services, 64.3% saw community services as either the same or better than they had initially, 64.3% gained at least some caregiver confidence, 50% were more committed to caregiving and the caregiver group. These gains were, however, in some cases unrelated and in other cases negatively related to attendance.

Becoming increasingly familiar with community services seemed to be an important factor for those in the group. Increased familiarity with services was strongly and positively associated with increased confidence in doing caregiver tasks (gamma=.733), with increased commitment to caregiving (gamma=.667), and with increased commitment to the caregiver group (gamma=.500). Interestingly, whether or not participants had become more familiar with community services was also quite strongly associated to their levels of income (gamma-.667). A negative association was found, however, between respondents' familiarity with community services and whether or not they changed their opinions about the adequacy of those services (gamma= -.400). Becoming more familiar with services was also totally unrelated to whether individuals expressed more willingness to perform typical caregiver tasks (gamma=.000).

Gaining confidence was also important to this caregiver group. Not only was increased confidence related positively to more familiarity with services (as noted above) but also quite strongly with commitment to caregiving (gamma=.777), and increased willingness to perform typical caregiver tasks (gamma=.500). Almost no association was found, however, between change in confidence and change in commitment to the caregiver group (gamma=.111). Some individuals apparently did not sense an important relationship between the caregiver group and their work as caregivers.

Except for being correlated to increased familiarity with services and increased confidence, whether participants increased in their levels of commitment to caregiving was quite unrelated to the major variables. Almost no association was found between change in commitment to caregiving and change in commitment to the caregiver group (gamma=.143), and none at all was found between it and increased willingness to perform typical caregiver tasks (gamma=.000). Interestingly, change in morale was negatively associated with changed caregiver commitment (gamma= -.455).

Change in commitment to the caregiver group did not take on the importance that it was expected to. It was somewhat associated to

increased familiarity with services (as noted above), but was negatively associated with change in perceived adequacy of services (gamma= -.455). The more inadequate individuals saw community services the more apt they were to increase their commitment to the group. It is noteworthy, too, that change in group commitment and change in morale were found to be negatively related (gamma= -.455). Increased commitment to the group did seem to have some impact on individuals' increased willingness to perform typical caregiver tasks (gamma=.333), however.

Improvement in participants' willingness to perform the many typical caregiver tasks was one of the major expectations of the project. The findings from the evaluation related to this variable show results that were much less than expected. As many as 57.1% of the respondents, in fact, expressed less total willingness after the training was finished than they had initially. Only 21.4% proved to be more willing than they had been initially (14.2% failed to indicate how willing they were on the post test). As noted above, increased willingness was not related at all to either attendance, increased familiarity with available services, or improved caregiver commitment. Neither was it related to change in how adequate respondents judged available services (gamma=.000). It was negatively associated with whether individuals were currently active caregivers (gamma= -.667) and with improved morale (gamma=-.333). It was only weakly related to increased commitment to the caregiver group (gamma=.333), somewhat more substantially to improved confidence in doing caregiving (gamma=.500), and quite strongly with informants' income levels (gamma=.714). Change in willingness was also quite substantially associataed with marital status (lambda=.417), with those who were married being more apt to express improved willingness than those who were widowed. In fact, none of those who were widowed said they were any more willing on the posttest than they were initially, while half of those who were married did.

Discussion

Our analysis indicates that few of the expected variable relationships were supported in the data. Further analysis of the variables and their relationships is needed to gain an understanding of why.

Attendance at the training sessions was expected to be a key factor in providing the informal caregivers with an awareness of and confidence in available outside professional help that is often needed, in helping them develop confidence in the caregiver tasks, and in giving them a greater sense of commitment to caregiving. It was also expected that attendance would provide the opportunity for participants to interact together and form a common group commitment and interdependency. Yet none of these factors seemed to come about because of attendance.

With regard to the lack of association between attendance and becoming more familiar with available services, at least two

explanations are possible. Since all participants attended at least half of the sessions and since a large majority of participants did, in fact, gain some familiarity, it may simply be that minimum attendance was enough to learn about available services. However, since some gained only slightly and since even some who had the better attendance records did not gain, perhaps more specific attention needed to be focused on this important factor in the training. Special emphasis would need to placed on the best possible access to each available service and what the most appropriate use of each would be.

The negative correlation between attendance and increased confidence in caregiving can probably best be understood by more closely examining the contents of the confidence variable. Participants were not asked to indicate their general sense of confidence about caregiving. Instead, they were asked to indicate how confident they were in perfroming a number of specific tasks that are often required of individuals caring for homebound long term care patients. Overall confidence was based on each person's cumulative score from all of the individual items. It is noteworthy that some of the tasks included require quite technical skills typically carried out by fully trained nurses and nurses aids. It would not be surprising, therefore, for informal caregivers to lack confidence in performing these tasks, even though they may sometimes be required by situational circumstances to do so. Neither could informal caregiver training be expected to adequately teach such skills or alleviate a lack of confidence in performing them. In fact, dealing with them in the context of this kind of training might indeed serve to make individuals feel even less confident than they had been initially. Probably what took place in this case was that those who attended the training, in fact, benefited from the training in a way that they should have -- being helped to sort out what they as informal caregivers can and what they cannot be expected to do. Those who attended less regularly than others may have felt more confident but missed that important lesson.

It is somewhat surprising that better attendance was negatively correlated to increased sense of commitment to both caregiving and to the caregiver group. The case may simply be that some individuals were initially quite highly committed and, therefore, would not be expected to substantially increase their levels of commitment, even though they had quite good attendance, while others may have begun with low levels of commitment but imporved even though their attendance was not the best. Since some with good attendance expressed even less commitment than they had initially, however, it may also be that more emphasis also needed to be placed on the importance of this factor in the training. Particularly important would be developing interdependent relationships between members of the group. This could well be a major focus of follow-up training.

That the extent individuals improved their judgements of the adequacy of community services was negatively associated with both attendance and improved familiarity with those services is somewhat

problematic. It might be, as suggested above, that more emphasis on community services in the training may have helped this situation. Yet, the data seem to indicate that better attendance and increased awareness and knowledge of the services tended to result in more, not less, skepticism about the adequacy of services. This may not be too surprising, though, when we understand that all but one of the five service agencies claiming to serve that small community were headquartered elsewhere and had county-wide responsibilities. In fact, it was this undesireable situation, typical of most small rural Arizona communities, that prompted one of the agencies (Catholic Social Services which was headquartered as far away as sixty-five miles) to initiate this project. Perhaps, then, these data indicate that participants were gaining a lesson in the realities of their situation, more than just being critical of their community. As it was initially assumed, services do not seem to be adequate to meet the needs, and the more caregivers learn about them the more aware they seem to become of that inadequacy.

Training for informal caregiving cannot in itself overcome the inadequacy. Organization is needed to help the caregiver group become as self-sufficient as possible and to create channels of easy access to the service agencies when that becomes necessary. That, in fact, has been one of the goals of the project, in addition to the training, but that part of the project was not part of this evaluation. Toward that end project leaders have begun and continue to work toward developing a case management system that will make at least one service agency ultimately responsible for every homebound long term care client in the community while relying on the informal caregivers for their day to day care. Perceived adequacy of community services will undoubtedly have to wait for the full development of that system.

Probably the most troubling results of this evaluation are those connected to changed willingness to perform caregiver tasks. The fact that a majority of participants expressed less willingness in the posttest than the pretest, and that it was unrelated to a number of key variables and negatively related to others would seem to indicate that something of a disillusioning process may have taken place during the training for some of the participants. That those who were married and those with the lower morale tended to express increased willingness more frequently than the widowed and those higher in morale would tend to support that possible premise. It is as though those who were married sensed that they had no choice but to be willing to provide the care their spouses may need now or in the future. Perhaps their willingness was related more to commmitment to spouse than anything else regardless of their low morale. The fact that commitment to the group was somewhat correlated with increased willingness may indicate that reliance on the group for support was reason enough to feel somewhat more confident about providing care.

A possible explanation for the decreased willingness on the part of some in the group is that the training may have served as something of a process of being liberated from the compulsiveness

that caregiving often takes on. In fact, that was the very purpose of one section of the training, entitled "Taking Care of Self." Participants learned that not only should they sort out what they could and could not do but also that they need not feel obligated to try to do all things needed by their caregiver clients or feel guilty for not being willing to try. In this case the data indicate that at least that part of the training was indeed effective rather than ineffective.

Summary and Conclusions

Even though the theory behind the evaluation of the Black Conyon City Informal Caregiver Project was not totally supported, the analysis indicate some very valuable results from the project. It also provides some important insights for improvement.

Clearly, as a result of the project many individuals became more knowledgeable and discerning about the availability and adequacy of professional services. Many increased their confidence and became more selective about doing cargiver tasks. The majority also became more committed to caregiving and to the caregiver group. Apparently, they also tended to learn to be selective in their willingness to serve as caregivers.

Some adjustments also seem to be suggested from the data, however. For one thing, more specific emphasis may be needed in the training on access to and appropriate use of available professional services. Almost certainly, more emphasis in the training ought to be placed on the importance of the caregiver group and on making it an interdependent mutual-self-help support system. This is an especially vital factor in communities like Black Canyon City where natural support systems seem clearly to be lacking. Then, much care needs to be taken in the training to eliminate what seems to be a dissolutioning process, on the part of some participants, resulting from some parts of the training.

Beyond the training, it is obvious that much careful planning and organizing is needed in order to make the group as self-sufficient as possible and to tie that caregiver system cooperatively into the professional care system, in order to maximize what both systems have to offer. An evaluation of these kinds of efforts being made in the Black Canyon City Project would be a valuable addition to this analysis.

It is fully realized that this analysis cannot be considered in any way conclusively definitive. It's value is that it has been exploratory, both in terms of the theoretical bases for such projects and in terms of how they ought to be organized and operated. It should provide valuable information on which to develop and evaluate similar projects in other areas.

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